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“Keeping it on your radar”—assessing the barriers and facilitators to a timely diagnosis of type 1 diabetes in childhood: A qualitative study from the early detection of type 1 diabetes in youth study

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Summary

Aims: The aim of this study was to explore from the perspectives of key stakeholders involved in the pathway to diagnosis, the barriers and facilitators to a timely diagnosis of type 1 diabetes in childhood.

Methods: Qualitative interviews and free-text analyses were undertaken in 21 parents with a child diagnosed with type 1 diabetes, 60 parents without a child diagnosed with type 1 diabetes, 9 primary healthcare professionals, 9 teachers and 3 community diabetes liaison nurses. Data were analysed thematically and 30% double coded.

Results: Two key themes were identified, namely the importance of widespread awareness and knowledge and seeking healthcare professional help. Parents with a child diagnosed with type 1 diabetes described seeking opinions from a number of individuals prior to seeking health professional help. Healthcare professionals recognized the rarity of the condition and the need for it to be kept on their “radar”, to ensure they considered it when examining an unwell child. The process of obtaining a primary healthcare appointment was identified as potentially playing a crucial role in the diagnostic process. However, most parents with a child diagnosed with type 1 diabetes described receiving an appointment on the day they sought it.

Conclusions: Knowledge and awareness of type 1 diabetes in childhood remain limited in the general population and misconceptions persist relating to how children present with this serious condition. An effective community-based intervention to raise awareness amongst key stakeholders is required to ensure children receive a timely diagnosis once symptomatic.

KEYWORDS

awareness, child, diabetes mellitus type 1, parents, primary health care, schools

1 | INTRODUCTION

A timely diagnosis of type 1 diabetes (T1D) in children is essential to prevent the life-threatening condition of diabetic ketoacidosis (DKA). Worldwide, the number of children diagnosed in DKA at onset of T1D ranges between 13 and 80%.¹ In the United Kingdom (UK), the rate has remained consistent over the last 20 years at 25% - 30%.²⁻⁵ Children under 2 years old are at three times greater risk of presenting in DKA at diagnosis.⁶ A prolonged pathway to diagnosis and lack of knowledge about T1D has been associated with greater psychological impact on parents, leaving them feeling emotionally traumatized and struggling to understand the diagnosis, particularly if their child presented in DKA.⁷ Furthermore, presenting in DKA at diagnosis places children at an increased risk of long-term morbidity and mortality^{8,9} and has led to the death of one child in the study area in the last few years.

The current literature suggests there are opportunities for an earlier diagnosis, with 285 of 735 (38.8%) children in DKA and 1104 of 3212 (34.4%) without DKA having had at least one medical encounter in the week prior to diagnosis.¹⁰ Explorations to understand what factors are associated with a delayed diagnosis have concentrated on retrospective accounts from primary healthcare practitioners and parents of children diagnosed with T1D.^{11,12} A recent systematic review of factors associated with DKA at diagnosis has highlighted a need for research that explores influences on parents' decisions to seek help to better understand how delays in obtaining a diagnosis arise.⁶

There are many factors that influence how quickly a child will be diagnosed once they start to display symptoms and many stakeholders involved in that process, such as parents, friends, family members, teachers, health professionals and primary healthcare staff. The aim of this study was to assess the barriers and facilitators to a timely diagnosis, by exploring the views of stakeholders 1 year after receipt of the Early Detection of Type 1 Diabetes in Youth (EDDY) intervention.¹³ The EDDY intervention was developed within the EDDY study, which was a study to design, develop and deliver a community-based complex intervention to raise awareness of the symptoms of T1D. The EDDY intervention was implemented in schools and general practitioner (GP) practices in three adjoining borough counties of South Wales, UK (Cardiff, the Vale of Glamorgan and Bridgend). The analysis reported here is novel in that it not only aimed to explore the accounts of GPs and parents who had a child diagnosed with T1D, but also sought to evaluate the thoughts and opinions of primary healthcare professionals, nursery and school teachers, and parents who have not had a child diagnosed with T1D, to understand their views on the barriers and facilitators to a timely diagnosis from a different perspective.

2 | METHODS

Ethical approval for the study was granted by Wales Rec 3 ethics committee 14/WA/1002.

2.1 | Participant sampling

Purposive and convenience samples were used to ensure representation from key stakeholder groups, namely parents with a child diagnosed with T1D, parents without a child diagnosed with T1D, nursery managers and school teachers, GPs and practice nurses (PNs) and community diabetes liaison nurses (CDLNs) who were responsible for delivering the intervention. Purposive sampling¹⁴ is a technique based on the researcher's own judgement of which type of participants to select from a specific population, whereas convenience sampling involves participants that are readily available. Potential participants were approached randomly, and researchers had no prior contact or knowledge of them.

2.2 | Parents with a child diagnosed with T1D

Paediatric diabetes specialist nurses from the two paediatric diabetes secondary care clinics serving the three study areas approached parents of children diagnosed with T1D to explain the study and seek permission to pass parent's contact details to study researchers. Only parents with a child attending a school or nursery within the intervention areas were eligible to participate. On receipt of contact details, parents were contacted by a CDLN or Cardiff University researcher (DG) to provide further information and discuss taking part. If acceptable, a home visit was arranged with the parent (or at a place of their convenience) to conduct the interview. Informed consent was sought prior to the start of the face-to-face interviews conducted by a CDLN or DG. A semi-structured interview schedule explored parents' experiences of their child's pathway to diagnosis, with particular emphasis on factors that may have influenced a timely diagnosis, for example, prior knowledge of T1D, symptom awareness and the role of key stakeholders.

Parents were recruited until data saturation¹⁵ occurred, resulting in 19 interviews with 21 parents; 10 parents had a child diagnosed before delivery of the intervention (between 4 months and 9 years) and 9 during the 5 months postintervention.

2.3 | Schools

A purposive sampling framework was developed that included nursery, primary and secondary schools from areas of both high and low deprivation. Deprivation was calculated from the school postcode and the Welsh Index for Multiple Deprivation (2014)¹⁶ lower super output area (LSOA) for each school. Schools were ranked as being either in a high or low deprivation area using the median score. Schools were also assigned a subjective assessment, based on the CDLNs' diaries, as to whether they were engaged or not engaged with the intervention evaluated in the EDDY Study.¹³ This subjective assessment was made by the researcher (JT) based on the reported difficulty or ease of engaging with schools to initiate the intervention. Adopting this framework allowed representation from at least one nursery, primary and secondary school from both high and low deprivation areas and assessed as engaged or not engaged.

2.4 | Parents of a child without T1D

A structured schedule was developed to evaluate the knowledge and symptom awareness of T1D of parents of a child without T1D. It was designed to be delivered face-to-face with parents of younger children (<11 years old) and through an online survey for parents of older children (>11 years old). Schools distributed the link to the online survey through their established channels of communication with parents. These included newsletters sent via email and text messaging. In total, 19 parents were interviewed at the school gates whilst dropping off or waiting to collect their children and 41 parents completed the online survey.

2.5 | Teachers and nursery managers

Schools and nurseries were approached to take part avoiding duplication of schools already selected for the parent of a child without T1D cohort. Interviews were arranged with those individuals deemed most appropriate by the school receptionist (head of school, head of year or the teacher responsible for first aid). Nine semi-structured telephone interviews were conducted with teachers and nursery managers to focus in particular on awareness and knowledge of T1D; symptoms and teachers' perceived responsibility for the health of children in their care.

2.6 | GPs and Practice Nurses (PNs)

A purposive sampling framework was developed of GPs and PNs based on the study area, deprivation of the area based on GP practice postcode, which CDLN delivered the intervention and a subjective assessment of whether the GP practice was engaged or not engaged, as described above. Initial contact with GP practices from the framework was by letter, followed up by email, to explain the study and offer a £150 reimbursement for their time if they participated. In total, 9 semi-structured telephone interviews were conducted, 4 with GPs and 5 with PNs. The schedule focused on the process of making a diagnosis (from the appointment procedure to patient examination), previous experience of T1D and potential delays in diagnosis.

2.7 | Data analyses

2.7.1 | Parents with a child diagnosed with T1D, Teachers and Nursery managers, GP and PNs

All interviews were audio-recorded and transcribed verbatim. Data were analysed by JT, DG and LC using thematic analysis as outlined by Braun and Clarke¹⁷ with the support of NVivo 10 software (QSR international), with 30% double coding to ensure consensus of emerging themes. NVivo is a piece of software that allows qualitative data to be organized and managed effectively. It also allows connections to be made within the data, for example, to particular themes.

2.7.2 | Parents without a child diagnosed with T1D and CDLNs diaries

Data collected using the structured schedule and online survey used a mixture of quantitative and qualitative methods. Only the qualitative results are reported here. The free-text responses were collected by researchers recording comments from parents with children <11 years old, free-text comments from the online survey from parents with children >11 years old and diary entries of the CDLNs. These free-text responses were analysed by JT and DG using thematic analyses and the MS Word's "spike" feature.¹⁸ This method allows the researcher to gather a number of different pieces of text, relating to a particular theme, at the same time and paste into a separate document.

3 | RESULTS

3.1 | Themes

Data analysed from all stakeholders yielded two main themes; (i) the importance of widespread awareness and knowledge, with a sub-theme of misunderstandings regarding T1D and T2D and (ii) seeking healthcare professional help. Further themes related to the acceptability and feasibility of the intervention are reported elsewhere.¹³

3.2 | Importance of widespread awareness and knowledge

Data from all stakeholders highlighted the importance of widespread awareness amongst the general public of T1D in childhood and the related symptoms.

During the pathway to diagnosis, parents would consult with a number of individuals, as well as seeking information via the Internet concerning their child's health and well-being, the outcomes of which could determine whether they sought professional help.

I'd discussed it with friends and my dad. And we'd all decided that it was basically just a phase she was going through and she'd come out of it... I still say to this day if it wasn't for [friend] she would have been a hell of a lot worse
(Parent with a child with T1D, 01/16)

The relationship between lack of awareness and a delay in seeking health professional help was emphasized:

I wish we'd seen a GP sooner. But that was, yeah, lack of awareness on our part
(Parent with a child with T1D, 01/14)

Often children can appear to be functioning well, which can delay help seeking, or parents are unaware of the seriousness of their condition.

I don't know whether I would have left it another week or two, in my mind I am thinking it was only because of

{mother in law} who said take him to the doctor... if it was me, would I have waited another week or so because he was so healthy... he was running around

(Parent with a child with T1D, 01/04)

Teachers reflected on the value of being aware of the symptoms of T1D and recognized that they were in a position to notice changes in children and to feedback to parents. This was especially evident in nursery teachers who viewed themselves as another caregiver and already reported to parents any concerns they had over the child's health behaviours.

We've got a specific team of girls that work with toileting, so they would bring it to our attention... because of the way the nursery is run, we would be well aware if the child was going...too frequently

(Nursery Manager, 01/206)

This relationship was reported to be maintained through primary school, with teachers stating that they would contact a parent if they had concerns with regards to a child's health and behaviour.

We'd maybe make enquiries with home and recommend perhaps a visit to the doctors to have something checked out... we can access the parent and we've got good relationship... and because children are with one teacher for a twelve month period, staff get to know the children very well, they would notice any changes in behaviour or health

(Primary teacher, 01/208)

There was an expectation on the part of parents that school staff would monitor child health and a belief that they are in a position to notice changes as they spend a large amount of time with them. Many parents spoke about discussing their concerns with their child's school and asking them to "keep an eye out" and report back, and many felt that the school should be knowledgeable about conditions such as T1D.

I said to her [teacher]... "she's changed, she's not herself, she's wetting the bed, she's not eating, she's not sleeping, have you noticed anything going on?" [she] told me no. Yet all these signs have been there all day and all night; it's not something she only suffers and shows at home, you know, so they could have picked up on those signs.

(Parent with a child with T1D, 01/10)

Alongside their own knowledge and awareness, GPs also expressed how important they think it is for parents to have awareness of T1D and its symptoms when undertaking a consultation with a parent regarding an unwell child and the influence that awareness can have on whether they carry out a diagnostic test.

I think the parental awareness is important... if a parent or carer asks [about T1D] of course it's going to bring it to mind...

it'll make you think about ruling it in or ruling it out. Increased awareness amongst everybody [facilitates a diagnosis], I mean parents, teachers, and rapid access to, if the question's raised, it's so easy to do a blood sugar... just awareness really...

(GP, 02/104)

As well as emphasizing the need for more wide-scale awareness throughout the community, GPs suggested that campaigns should be repeated at regular intervals to ensure T1D is kept at the forefront of their minds.

To keep it on the radar to be honest

(GP, 01/106)

The following parent's account of her child's diagnosis journey highlights the range of individuals who may play an influential role in the pathway to diagnosis and why it is important that there is widespread awareness across the board.

She had like a couple of viral, well, what the doctor said were viral infections. So I took her to the doctors a few times and I said, "look I'm a bit concerned, she's losing weight, didn't have much of an appetite, was having problems with the sleeping as well". And also... one of the things the school had noticed, she was starting to get really naughty, she had what I described as fits where she was hysterical. And then I noticed she was waking up and drinking a lot in the night. And school said to me, "look, we're a bit concerned because every five minutes she's going for a drink of water". And then...when it was her birthday, she was ill... everyone said "god, she looks awful she's really lost a lot of weight". Took her back to the doctors again and I said "I'm really concerned now, this can't be right" but she didn't seem to think it was anything bad. It must have taken a good three or four months really of me constantly going back [to the GP]. And what annoyed me is that I gave the same symptoms every time. Tiredness, thirst, weight loss, weeing, all these kinds of things. I kept telling them it and it still never occurred to them to say let's check her sugars

(Parent with a child with T1D, 01/17)

3.3 | Misunderstanding between T1D and T2D

Data provided by parents without a child with T1D and school teachers highlighted the limited level of knowledge of T1D, symptoms of T1D and confusion between Type 1 and Type 2 diabetes (T2D). Many assumed that T1D is caused by lifestyle factors or dietary behaviours.

I think they [school staff] were all quite shocked that children can actually get diabetes 'cause they all think that's an old, fat person's disease

(Nursery manager, 02/201)

Parents surveyed in schools often felt they had some knowledge of T1D but many were unable to provide an explanation of symptoms or what the condition meant, and some gave inaccurate reports such as T1D being a result of “eating too many sugary and unhealthy foods”.

My children drink fizzy drinks as a treat...When I noticed that my child was putting on excessive weight I started to think about what I was feeding them at home and school and talked about cutting down on puddings, sweets and fast foods.

(Parent without a child diagnosed with T1D, 01/624)

Experiences of parents prior to diagnosis of their child and the knowledge of third parties were usually from knowing someone with T1D or working somewhere where they may have received relevant training, for example health care or education. However, many spoke about having no awareness of T1D or as a result of media coverage of T2D, assumed diabetes was related to being overweight and having an unhealthy lifestyle.

Diabetes is such a familiar word, everybody knows someone with diabetes. In the majority of cases, it's probably Type 2.... Our misunderstanding was that Type 2 evolved into Type 1 if it got worse

(Parent with a child with T1D, 01/14)

3.4 | Clinicians' awareness, perceptions and knowledge

Although clinicians had a high level of knowledge about T1D, the related symptoms and often described thorough assessment and testing procedures in their consultation with children, CDLN diaries noted there could still be misunderstandings about the seriousness of the condition amongst health professionals and a lack of awareness of DKA in particular. There was also a misconception over how sick children would appear if they were in DKA.

We see so few of these per practice... I'm just wondering really how many patients are we missing, because you really can't miss these kids... I can't imagine there can be that many cases of DKA that are missed through lack of awareness

(GP, 02/104)

Parents also recounted how shocked their GP was at diagnosis at how “well” the child appeared.

He (GP) said, 'I can't believe that he has gone to school fine and he has done PE and he is awake and he is talking to you

(Parent with a child diagnosed with T1D, 01_02)

Clinicians' perceptions about prevalence and the “obviousness” of T1D could influence clinicians' awareness of the condition in terms of their likelihood to test for it or suspect it whilst assessing a sick child. The CDLN diaries and clinician interviews suggested that many clinicians had no experience of diagnosing T1D in a child which impacted their beliefs about how likely they were to see a child with this condition.

Not thinking about it [hinders a diagnosis], not having it in the forefront of our minds. And then I suppose the infrequency of finding it, you know, the infrequency of presentation because of course things that aren't common, it [T1D] isn't common in children and because it's infrequent I suppose you're less likely to think of it

(Nurse, 01/101)

3.5 | Seeking healthcare professional help

GP surgery receptionists were identified as playing a key role regarding parents' ability to access an appointment. Although clinicians emphasized that receptionists were not responsible for triaging patients, it was highlighted in both parents' and clinicians' accounts that receptionists were the first point of contact for parents seeking an appointment; responsible for assessing the urgency of the situation and influencing allocation of appointments to a GP or PN.

They are kind of dragons, the receptionists, aren't they, sometimes to get through, but I think my husband had just stressed, "you know my daughter's been extremely ill. I need this appointment now." And luckily for us he got an emergency appointment that morning but I think by having it with the nurse, rather than the doctor, that was the compromise that we were seen so soon

(Parent with a child diagnosed with T1D, 01_19)

Clinicians reported that children were recognized as a vulnerable group and stated that extra considerations are made when allocating appointments, often erring on the side of caution, especially with younger children. Some practices had implemented a triaging policy where the on-call GP would telephone concerned parents, to assess whether the child needed to be seen urgently. However, clinicians acknowledged how parents could influence the necessity of a same day appointment.

I think we would be guided by the carer or the parent

(GP, 01_107)

Only one parent recounted accessing help from an additional healthcare source by contacting NHS Direct; however, this did not influence their ability to obtain an appointment that day.

I rang the GP Practice that I was going to register with here, but they couldn't see her because there wasn't any

appointments left. So when I went to go and pick up [child] from school, [friend] said, "Ring NHS Direct." ... and the lady on the phone was absolutely fab and she said "Right I'm going to ring your GP Practice and see if I can get them to see you". ... she rang me back and said no the GP has said that they can't see her today. But because of the symptoms that you're telling me about, ... my advice to you is to take her straight to the nearest A & E.

(Parent with a child diagnosed with T1D, 01_16)

Nevertheless, most parents who had a child diagnosed with T1D recounted that they did get an appointment on the first day they phoned.

4 | DISCUSSION

This is the first study, to our knowledge, to seek perspectives of parents and teachers who appeared to have little or no prior lived experience, knowledge or awareness of the symptoms of T1D in childhood.

Previous studies have focused solely on the retrospective experiences of parents with a child diagnosed with T1D; children with T1D and primary healthcare professionals.^{11,12} By conducting a study with other key influential individuals, we can get a better understanding of the complex barriers and facilitators that impact on ensuring a timely diagnosis of T1D.

Overall, the study highlights a general lack of awareness and knowledge of T1D, as well as a number of misconceptions relating to its presentation. Confusion over the difference between T1D and T2D appears to be widespread in the general public,¹⁹ and our results support these findings. This is possibly due to the high level of media attention given to T2D over the past decade, following governmental strategy and policy to prevent T2D,²⁰ due to the growing obesity crisis in the UK.²¹ In a study of adults with T1D, individuals reported stigmatization from friends, family and healthcare professionals, due to the misplaced perception that affected individuals were responsible for developing the condition through lifestyle choices.²² These findings suggest public confusion exists in understanding the differences between T1D and T2D which has the potential to increase delay in diagnosis. This may occur through individuals not understanding the seriousness of T1D if not diagnosed promptly or not realizing T1D is a condition that can affect children. In addition, because T2D is associated with obesity, individuals may not consider weight loss as a precursor to a diagnosis of T1D.

Parents draw on a variety of members from their social networks that have the ability to both influence or hinder their decision to seek healthcare professional help, when their child is unwell.^{23,24} Kai (1996) reported that parents assessed the level of illness of their child using both behavioural and symptomatic clues against what they considered normal for their child. As many children with symptoms of T1D can appear "well," that is drinking, eating and functioning, it is unsurprising that many parents do not consider T1D as a possible diagnosis or understand the potential seriousness of the condition if left untreated.

Our findings from parents with a child already diagnosed with T1D echo previous research where lack of awareness and knowledge led to delayed diagnoses.¹² However, our results differed from their findings that parents who articulated symptoms to their GP received a prompt diagnosis. This emphasizes the need to raise awareness across all stakeholders and regularly "top up" information, to ensure that it remains on everyone's "radar".

Despite some studies identifying the receptionist at GP practices as an unhelpful "gatekeeper" to patients obtaining an appointment,²⁵ much of the literature presents a more balanced view recognizing the complexities of managing patient requests for appointments as well as GP and PN workloads.²⁶⁻²⁸ Research on the interactions between patients and receptionists is limited, but a study of three UK GP practices where 2780 phone calls of patients seeking appointments with a receptionist were analysed identified the concept of "patient burden". This concept recognizes that it is the patient that has to drive for a successful outcome during the appointment making process, rather than the receptionist proffering solutions.²⁹ These findings are consistent with our data which recognized the influence of the carer on successfully obtaining an appointment.

Results from our study emphasize that knowledge and awareness of T1D within the general population remain poor. In addition, misconception of the prodrome of T1D by some primary healthcare professionals persists. There have been several interventions around the world, designed to raise awareness of the symptoms of T1D, which have had mixed success.^{5,30-32} Overall, our results demonstrate the important roles that a range of individuals can play in the pathway to diagnosis, highlighting the need to deliver an effective community-based intervention to raise awareness of the symptoms of T1D in childhood.

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NOVELTY STATEMENT

- This novel study explores the perspectives of key stakeholders involved in the pathway to diagnosis of type 1 diabetes in childhood
- Qualitative research methods indicate the importance of widespread awareness of the symptoms of type 1 diabetes, as parents attain the opinion of a number of significant individuals, for example friends, family, teachers, prior to seeking medical help.
- Misconceptions regarding the condition and confusion over the difference between type 1 and type 2 diabetes persist within the public and primary healthcare professionals
- Results indicate the need for an effective publicity campaign targeting the public and primary healthcare professionals

CONFLICT OF INTERESTS

Nothing to declare.

AUTHOR CONTRIBUTION

JT, DG, LC and CH recruited participants and collected data. JT, DG, LC and LL analysed the data. LL, JG, SC and JT initiated the project, designed the research methods and analysed the data. MR, SM and DW initiated the project and designed the research methods. All authors drafted and revised the paper.

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